NEBRASKA HEALTH AND HUMAN SERVICES SYSTEM

NEWBORN SCREENING FACT SHEET

POSITIVE HEMOGLOBINOPATHY SCREENING TEST RESULT FOR SICKLE CELL-BETA THALASSEMIA DISEASE

WHY DO WE SCREEN BABIES FOR HEMOGLOBINOPATHIES?

Hemoglobin is the chemical inside red blood cells that carries oxygen. Some people have a change in their hemoglobin. In some cases, like sickle cell trait, this causes no problems. In the cases of sickle cell disease or sickle cell-beta thalassemia, babies need early medical attention to prevent serious, or even life-threatening, problems.

WHAT DOES A POSITIVE SCREENING TEST FOR SICKLE CELL-BETA THALASSEMIA DISEASE MEAN?

Hemoglobin, like all other proteins in your body, is made from instructions contained in your genes. Each gene has two copies. Sickle cell trait occurs when one copy of the gene for hemoglobin is abnormal, and there is no disease. If your baby inherits one copy of the gene for sickle cell and one copy of the gene for thalassemia, then your baby has sickle cell beta-thalassemia disease. (People inheriting sickle cell genes in both copies have sickle cell disease).

Screening tests are used to separative those who almost certainly do not have a disease, from those who are more likely to have a problem. Your baby's positive screening test means that additional tests must be done to determine a diagnosis.

HOW CAN *SICKLE CELL BETA THALASSEMIA DISEASE* AFFECT YOUR BABY'S HEALTH?

This disease is like sickle cell disease. It is a lifelong condition that can cause severe anemia and other problems children with sickle cell disease sometimes get. These problems may include stroke, lung damage, and painful crises. These children are also at risk for serious infection. They need to take antibiotics to lower their risk of infection.

WHAT SHOULD A PARENT DO WITH THIS SCREENING TEST RESULT?

In order to find out whether or not your baby has sickle cell beta-thalassemia, you and your baby's doctor need to discuss the test results and to get additional testing for your baby.

WHO CAN I CONTACT FOR MORE INFORMATION?

You can obtain more information from your baby's doctor about abnormal hemoglobins and other specialists available. Genetic counseling to discuss testing options and family risks for hemoglobin problems is available through clinics at various sites around the state by genetics specialists from UNMC. To schedule an appointment, you can call (402) 559-6800 or (800) 656-3937. Specialists in Hematology are available at: James Harper, MD- UNMC (402) 559-7257; David Gnarra, MD-Children's (402) 955-3950, Dr. Howard Koch-Alliance (308) 762-2125.